

# Towards End-User Development for Chronic Disease Management

Daniel Rough  
SACHI Research Group  
School of Computer Science  
University of St Andrews, Scotland  
djr53@st-andrews.ac.uk

Aaron Quigley  
SACHI Research Group  
School of Computer Science  
University of St Andrews, Scotland  
aquigley@st-andrews.ac.uk

**Abstract**—Although developments in modern medicine continue to reduce premature death from acute illnesses, chronic diseases are now pervading the resultant aging population at a growing rate. Such diseases cannot be cured with drug-based treatment, but can be controlled with patients’ regular monitoring of their symptoms and consequent lifestyle changes. However, this level of sustained engagement outside face-to-face appointments places a considerable burden upon patients. Smartphones are suitable platforms to support both patients in engaging with self-management plans, and clinicians in directly monitoring the influence of these plans. Bespoke applications exist for such purposes, yet the diversity in patients’ lifestyles and levels of engagement necessitates many new or personalised applications. One approach, to solve these problems at scale, is with end-user development. This paper reports the findings from interviews with clinicians, and ethnographic observation in chronic disease management clinics, to derive requirements of end-user development technology to support clinicians and patients in tailored management of their diseases. Time and quality are key factors towards stakeholders’ acceptance of chronic disease management with end-user development.

## I. INTRODUCTION

Medical research continues to fight a winning battle against acute deadly diseases. However, the global reduction of *acute* infectious diseases such as smallpox, malaria, measles and polio, has increased overall life expectancy, giving rise to a dramatic increase in the problem of *chronic* diseases. According to the World Health Organization (WHO), global life expectancy increased by 5.5 years from 2000 to 2016<sup>1</sup>. In parallel, almost 60% of worldwide deaths and 43% of the global disease burden are attributed to chronic diseases - figures expected to rise to 73% of deaths and 60% of global disease burden by 2020<sup>2</sup>. With a disparate range of causal factors, various social and economic influences, and no clearly delineated solution, this chronic disease pandemic is, by definition, a “wicked problem”.

Technological innovations have transformed the effectiveness of healthcare around the world. Examples such as MRI scanners, laser eye surgery, or bionic hands may spring to mind, but these are undisputed solutions to “tame problems”. In this paper, we instead draw attention to technology that can support human-centred communication and collaboration towards developing better approaches to patient management. From an organisational perspective, patient records and pre-

scriptions can be digitised for ease of access and transfer across different practitioners. In terms of diagnostics, wearable devices that quantify and summarise health data such as blood pressure and heart rate can be used to monitor patients more effectively. Smartphone apps are now being developed that can trigger emergency actions based on physiological data, such as automatically calling emergency services when the onset of a heart attack is detected [1]. The expanding opportunities afforded by mobile health technology have even empowered patients to monitor and manage their own conditions, independent of clinician involvement. With increasing hospital waiting times, and the prevalence of chronic diseases in the global population, the UK’s National Health Service (NHS) has already begun to act on these potential benefits, through introduction of an NHS-certified app library<sup>3</sup>.

While bespoke apps can help chronic disease patients control their symptoms and effectively provide a solution at an individual scale, the diversity in symptoms, lifestyles, socio-economic status, and self-efficacy of these patients in managing their conditions, all preclude a “one-size-fits-all” app solution. Thus, we propose that this problem is ideally suited to end-user development (EUD) technology, where flexible software can be tailored to the requirements of its end-users and adapted dynamically as required. Allowing clinicians to collaborate in the development of disease management apps, personalised to individual patients, would enable a human-centred approach to solving this problem. Indeed, sufficiently motivated patients could themselves engage in EUD activities.

The contribution of this paper is a qualitative analysis of clinician interviews, and observation of nurses running chronic disease management clinics, from which a set of requirements are derived for EUD technology in the management of drug-resistant chronic diseases. In particular, our results address:

- Stakeholders’ perceived utility of EUD as a novel form of human problem-solving (*perceived potential*)
- Challenges with respect to patient-clinician communication, as well as inter-clinician communication (*workflow requirements*)

1. [www.who.int/gho/mortality\\_burden\\_disease/life\\_tables/situation\\_trends\\_text](http://www.who.int/gho/mortality_burden_disease/life_tables/situation_trends_text)
2. [www.who.int/chp/about/integrated\\_cd](http://www.who.int/chp/about/integrated_cd) Accessed 27/06/18
3. <https://digital.nhs.uk/nhs-apps-library> Accessed 17/03/18

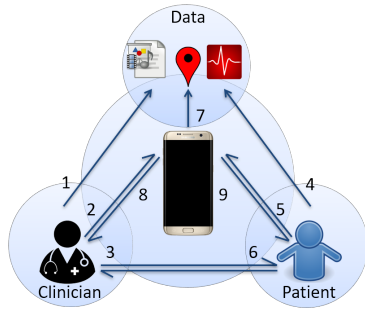


Fig. 1. Various interactions between clinicians, patients, and apps are required

- Organisational factors required to support integration of this technology into current working practices (*facilitating conditions*)

## II. RELATED WORK

*“The use of mobile and wireless technologies to support the achievement of health objectives (mHealth) has the potential to transform the face of health service delivery across the globe”* [2]

This quote from the WHO’s report on mHealth innovations exemplifies how app-based solutions to health service issues are being taken seriously by global organisations. Indeed, there are now over 325,000 health-related apps available for download [3], provoking concerns about the lack of evidence-based information in the majority of these apps, and the associated dangers of misinforming their users [4]. In particular, we focus on apps for assisting in non-communicable disease management, which do not directly solve problems in themselves, but instead facilitate “human problem-solving” by encouraging self-reflection, and enabling understanding between patients and clinicians.

A literature review was conducted within computer science literature databases including the ACM, IEEE, and Scopus digital libraries, as well as the PubMed Central and APA PsycINFO databases, using combinations of terms including ‘smartphone’, ‘self-monitoring’, ‘self-management’, ‘experience sampling’, ‘user-centred’, ‘participatory design’ and ‘recommendations’. Particular insight was obtained from user-centred design studies that highlighted stakeholder perceptions of smartphone apps for self-management, prompting the addition of the latter three terms.

From this review, a variety of interactions between patients, clinicians, and apps themselves were proposed, as illustrated in Figure 1, representing an evidence-based set of features for general-purpose disease management technology. Arrow numbers correspond to the following numbered descriptions of each interaction.

### Clinician Interactions

1) *Viewing real-time patient data:* Instant access to self-monitored patient data could guide treatment decisions in face-to-face clinical appointments. Study participants living with

cystic fibrosis [5] and attention disorders [6] both strongly supported the provision of contextual information to clinicians. In an evaluation study of an app where such information access was implemented, pediatricians described how this saved time, focused appointments, and facilitated communication about difficult issues during these appointments [7].

2) *Updating management plan in real-time:* Studies that cite the benefits of smartphone-based self-management all describe bespoke apps developed for the specific purpose of each study. Hence it appears that, although these benefits are generic and adaptable, their implementations are not. Thus, the researcher must be able to adapt these features found in bespoke apps to any study they choose to run. In doing so, they perform end-user development (EUD) activities. While there are few studies addressing this interaction, the work of Tetteroo and Markopoulos addresses EUD for rehabilitation therapists to design exercises for their patients [8].

3) *Providing feedback to patient:* In user-centred design studies of healthcare apps, feedback provision from clinicians to patients was extensively discussed. Given that clinicians have very little time outside of scheduled appointments, there was surprising enthusiasm for this type of interaction. For example, it was recognised that in-the-moment professional assistance on coping with cancer-related pain, prompted by self-assessment data, would support sustained engagement with self-monitoring [9]. Clinicians also suggested that feedback would not have to be a time-critical intervention, and were enthusiastic about providing regular feedback to patients on their data [10]. In an implemented trial, clinicians valued a feature allowing response to alerts on patients’ symptoms of potential heart failure, suggesting that the initial workload involved in responding to these alerts would be reduced in the long-term by minimising unnecessary hospital admissions [11].

### Patient Interactions

4) *Viewing aggregated, collected data:* Sophisticated sensing and growing storage capacity of smartphones enable rich visual charts of objective, historical data to be displayed. Visual feedback could raise engagement in patients with chronic health conditions. Participants trialling the *MONARCA* system valued both the ability to correlate their moods with objective data, and to determine the temporal antecedents of low moods [12]. Users with chronic conditions expressed interest in viewing their passively sensed information, particularly in the form of visual graphs, supported by participants with mixed chronic conditions [13] and diabetes [14].

5) *Tailoring app to personal preferences:* Despite the motivational influence of empowerment to self-manage, maintaining a high level of engagement with apps is still a significant challenge. mHealth apps are easily removed or forgotten about, and patients thus must perceive sufficient value from use if they are to retain engagement. Indeed, recent statistics illustrate that a quarter of apps downloaded are only used once<sup>4</sup>. A balance must be sought between ensuring that app

4. <http://info.localytics.com/blog/24-of-users-abandon-an-app-after-one-use>

content is based on the input of a professional, while also respecting the preferences of its end-users. User-centred design studies of health apps have elicited the importance of flexible prompt schedules to end-users [15], [16]. Moreover, end-users also desire the ability to control the content of feedback that they are provided with [12], [13], as well as the format in which this feedback is presented [6].

6) *Providing feedback to clinician*: While visual feedback and personalisation are both useful features for improving engagement, certain issues relevant to patient care may require a direct channel of communication to clinicians. As such, “*healthcare partnership*” was an emergent theme in one focus group study [13]. Focus group participants expressed a desire to contact clinicians for additional explanation of their received feedback. Involving clinicians in this “*sense-making*” process was proposed to support patients in attaining maximum benefit from their management plans. Additionally, individuals with cystic fibrosis identified how self-monitored data would enable them to provide feedback to clinicians between appointments [5].

### App Interactions

While supporting human problem-solving by definition relies on ensuring humans can make decisions, actions that can be made automatically by smartphone apps can provide knowledge for human decision-making at key times.

7) *Receiving and classifying data*: Self-reports can assess intentions, attitudes or certain subjective physical symptoms (such as discomfort or pain). However, an increasing breadth of information can be objectively assessed from sensors built-in to the smartphone, or externally worn. In doing so, passively collected sensor data can minimise self-report burden, provide researchers with richer information, and enable tailored assessment and intervention strategies. For example, Ben-Zeev et al. showed that smartphone-sensed geospatial activity and sleep duration were significantly related to stress levels in a cohort of young people [17]. Adams et al. review smartphone sensing for monitoring physiological and behavioural biomarkers, providing a comprehensive source of examples [18].

8) *Sending alerts to clinician*: From knowledge acquired through subjective and objective data, disease management apps could inform clinicians of in-the-moment issues or emergency situations. In many conditions, early detection of symptomatic pre-cursors can prevent fatal consequences through clinician intervention. In a user-centred study on app requirements, clinicians and cancer patients both supported a feature to alert clinicians when patients reported high levels of pain [9]. Clinician alerts were also implemented in a randomised control trial, where physiological readings transferred to smartphones via Bluetooth, combined with patients’ symptom reports, alerted clinicians to heart failure pre-conditions [11]. The trial reported improved health outcomes, with patients expressing feelings of reassurance and self-efficacy, and clinicians confirming the utility of alerts.

9) *Sending notifications to patient*: Interventions could be dynamically delivered at locations of interest or on physiolog-

ical measures. For example, the *Q Sense* app deployed tailored interventions when participants dwelt in identified smoking locations, with post-study feedback exhibiting positive response towards location triggers, and tailored messages [19]. For self-management, users with chronic conditions valued the possibility of contextual reminders, such as those prompted at a particular location [5], [16]. One study had participants describe their physical activity after levels of intense activity, or extended non-activity, were detected with a smartphone accelerometer [20]. From a healthcare perspective, this increased self-awareness could promote positive behaviour [21].

### Summary

The cited studies employ user-centred design to solve “tame”, albeit non-trivial problems of developing engaging healthcare apps for particular conditions. We suggest that for chronic disease management apps to be effective on a global scale, the extent to which these features are utilised should be determined by clinicians and patients themselves, shifting from design *before* use to design *during* use [22].

However, developing EUD tools that support stakeholders in their current practice, and evaluating the success of these tools in doing so, are major challenges, which require investigation beyond usability studies. In real-world deployments, an individual’s interactions with technology are highly dependent on others who form part of their working practices, and existing technologies in this environment. These factors are diverse and dynamic, such that continuous communication and collaboration are necessary to ensure that deployed technology evolves with an environment and the people within it. As a result, the approach taken here was to elicit direct feedback from clinicians, as the potential users of EUD technology.

### III. INTERVIEWS

Semi-structured interviews were conducted with eight practising clinicians in our university’s school of medicine. Interviews took place at the interviewees’ location of choice, lasted approximately 45 minutes, and were audio recorded. The recordings were then transcribed, and qualitatively coded for thematic analysis. Coding was structured based on the addressed themes specified in the introduction, which were linked to constructs in validated models of technology acceptance, specifically the Technology Acceptance Model, as shown in Figure 2, and the Unified Theory of Acceptance and Use of Technology [23]. In doing so, factors pertaining to the real-world adoption of chronic disease management EUD were identified. The relevant constructs of these models are *perceived usefulness* (which is further divided into *perceived potential* and *workflow requirements*) and *facilitating conditions*. These themes are defined as follows.

- 1) **Perceived potential** - Clinicians were given a brief overview of an existing EUD tool, and asked for feedback on the perceived utility of EUD for disease management.
- 2) **Workflow requirements** - Clinicians were asked about their current practices in dealing with patients managing

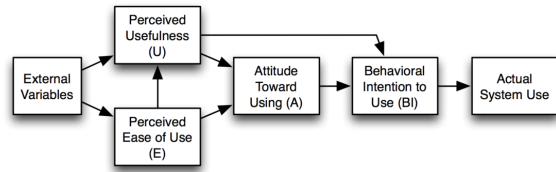


Fig. 2. The Technology Acceptance Model [25]

TABLE I  
PERCEIVED BENEFITS/BARRIERS OF EUD TECHNOLOGY FOR CHRONIC  
DISEASE MANAGEMENT, BY CLINICIANS AND PATIENTS

Stakeholder	Perceived Benefit	Associated Barrier
Patient	Patients more independent	Incapable patients at risk of being forgotten
	Patients empowered to self-monitor	Patients are diverse in self-management needs
Clinician	Clinicians can track patients' progress	Diverse data can overload an individual clinician
	Clinicians acquire more accurate data	Patients may be burdened by extra self-monitoring

chronic conditions, with emphasis on activities that would need to be supported.

- 3) **Facilitating conditions** - Clinicians discussed the practical issues of integrating novel technology into an existing healthcare system.

Although we demonstrated our specific EUD tool, *Jeeves*, to clinicians in the interviews, the feedback elicited focused on broader issues of its integration into an existing healthcare system. Factors pertaining to existing features of *Jeeves* are discussed in further detail in our work with psychology researchers [24], and instead the hypothetical features derived in our related work were used as prompts for idea generation in these interviews.

The clinicians interviewed consisted of five general practitioners (GPs), a pharmacist, an ophthalmologist, and a clinical psychologist. A diversity of roles, responsibilities, and opinions with respect to patient care were thus exposed.

#### A. Perceived potential

Although clinicians and patients are two distinct stakeholders, the potential for improved patient health outcomes would reciprocally benefit the clinicians themselves, in terms of reducing unnecessary appointments and freeing up clinic time. However, opinions regarding the effect of smartphone-based self-management on time were varied, with some clinicians concerned that their workload would be increased. Potential benefits and barriers are summarised in Table I.

C4, a GP, explained the benefits of a *holistic* model of care that takes patients' psychosocial issues and lifestyle habits into account. However, time-constrained appointments, and pressure to see as many patients as possible, means that GPs often rely on quick prescriptions of medication to avoid

overrunning on clinic time. A further aggravating issue is that appointment slots are often used for simple reviews:

*"I certainly feel like we do epilepsy reviews face-to-face which could be done remotely. Because a lot of that is asking questions or providing advice which actually you don't need to physically be in the same room as somebody to do that"*

Thus, when face-to-face diagnoses are not required, as in these epilepsy reviews, self-management technology could increase appointment slots for acutely unwell patients.

Clinicians further explained that patients were often poor at reporting their symptoms and summarising their experience over a number of weeks:

*"the doctor sees them every two weeks so then some patients they tell them 'how was everything during the two weeks?'; 'Yes everything was alright'...because then time passes and patients tend to forget"* (C2)

Irrespective of patients' memory bias, the act of taking an individual reading in a clinical setting is insufficient to characterise the overall status of the patient. C8 explained how, for diabetic patients, a single "HBA1C" reading is relied upon to derive longitudinal information:

*"we're relying on one single value of this HBA1C so...you might know that the patient has not been well-controlled but you don't know why..."*

#### B. Workflow requirements

Although the perceived potential of EUD technology was evident from clinicians' feedback, a number of requirements were addressed towards the workflows and communication that would need to be supported. Such requirements, and barriers in Table I that they would address, are shown in Table II.

1) **Technologies should make it easy for clinical staff to communicate and collaborate with each other:** Chronic disease patient care is a collaborative effort between GPs and specialist practice nurses. Clinicians explained how individual diseases were dealt with by nurses who had received specific training for management of that disease. Patients may also see different doctors, so it is important to enable collaboration and understanding between clinicians. Current technology does not provide a simple means of doing so, as expressed by C3, a clinical psychologist:

*"if we make a change to patients' medication, the quickest way to communicate that to the GP is to fax them, would you believe. So, if we email the GP, we have no idea when the GP might pick that up"* (C3)

It also emerged that comorbidities would need to be taken into account. Patients with a chronic disease such as diabetes often have a coexisting disease such as asthma or hypertension. While one nurse would be capable of authoring an action plan for managing a patient's diabetes, this would require input from an asthma nurse if such a comorbidity was present.

2) **Technologies should support patients' current self-monitoring:** Clinicians also expressed positive opinions with respect to the feasibility of self-monitoring, given that many patients are already engaged in doing so. It emerged that

TABLE II  
EUD WORKFLOW REQUIREMENTS FOR INTERVIEWED CLINICIANS

EUD Support	Barrier Addressed	Functionality Required
Clinician collaboration	Patients are managed by many clinicians who need specific types of data	Community support, including shared editing + collaboration functions
Monitoring Integration	Patients may be burdened by additional work on top of current self-monitoring	Simple integration with existing monitoring equipment and routines
Individual Tailoring	Patients are diverse in their personal management needs	Protocols that are tailored to stages of patient independence
Personalised Reminders	Dependent, incapable patients are at risk of being forgotten	Prompts delivered at times personalised to patients' preferences

patients with chronic diseases are often highly skilled in their management, and willingly purchase monitors to facilitate their independence. In order for new technologies to become an asset to their healthcare, rather than a burden, it should be possible to integrate technologies with patients' current self-monitoring practices. It was suggested that Bluetooth and other wireless data transfer technology could enable patients' results to be seamlessly uploaded from their existing devices.

3) **Technologies should allow tailoring to individual patients:** A patient-centred care approach relies on the incorporation of patients' own goals, motivations and constraints, which determine whether or not they are likely to engage in treatment. C6 described these factors as the patient's "agenda":

*"Healthcare people, not just doctors, have agendas, but the patients often come in with a totally different agenda, so it's about sorting out what the patient's agenda is and how you can use that to improve their physical wellbeing."*

4) **Technologies should support personalised reminders:**

For the inevitable cohort of patients who would not engage in self-monitoring, it should be simple to set up reminders for different aspects of their healthcare. C3 mentioned that either patients themselves, or their carers, would add appointment reminders on their mobile devices.

*"Interestingly quite a few of our patients say they've set reminders on their phone for things like daily reminders of it's time to take their medication. So they've actually done that themselves, or somebody's usually done it for them..."*

Additionally, many of these patients are required to take medication at particular times in their daily routine. C8 suggested that it should be possible for patients to input their waking and sleeping times, as well as regular mealtimes, to ensure that medication is taken.

### C. Real-world integration

In the context of clinical practice, constraints imposed by the NHS present significant barriers to EUD adoption in the UK. Healthcare transformation is difficult in a system where it must take place at a national level. Thus, facilitating conditions must be fulfilled to enable the transition from clinicians' *intention to use* to their *active usage behaviour* [23].

1) **Clinicians must be allowed time to get used to new technologies:** Although time was a critical factor across all clinicians, GPs in particular reported a lack of time given their high workload. Ironically, clinicians would struggle to adopt time-saving technology because the initial time to introduce it would be too costly, as expressed by C4:

*"...I know that takes like a minute or two, it's a minute or two I might not have. The times are very very precious...this will free up time ultimately. But it's that initial jump, isn't it?"*

GPs expressed frustration that, paradoxically, they need more time to discuss general health management that would reduce unnecessary appointments. However, this high number of appointments forces them to limit individual patient time to 10 minutes.

2) **Clinicians must trust the resilience of apps developed with EUD:** From a technical perspective, clinicians were wary about the reliance on technology to capture abnormalities and give patients immediate feedback at critical times. Quality assurance of smartphone apps is critical in a medical context, where the health and well-being of patients could potentially be put at risk. Clinicians had concerns about what would happen if such an app were to malfunction:

*"if suddenly you don't have network coverage, then your reading might not get to the platform or whatever or the server in two hours, and then if it's a high reading...you might not be able to receive the message soon enough"* (C8)

In summary, the clinician interviews gave further insight into the types of interactions that would be required to support effective human problem-solving in chronic disease management. In order to strengthen the ecological validity of these findings, it was necessary to observe the current practices of clinicians involved in this domain.

## IV. OBSERVATION

An observation session was conducted over two hours at a local clinical practice, with one hour assigned to both a nurse running a diabetes clinic, and a nurse running a hypertension clinic. Within each hour, three patients were seen by both nurses. Audio recordings and computer use were not permitted within the clinical setting. Instead, notes were hand-written during the observation sessions, transcribed and expanded on within 24 hours of the recording process. The observation sessions were *naturalistic*, in that the observation aimed to disrupt the process as little as possible.

### A. Diabetes management clinic

The observations made during the diabetes management clinic are divided into the following themes: self-management, salient problems, and technology use.

1) **Self-management:** The nurse explained that, contrary to the stereotype of older patients being less accepting of patient-centred care, diabetic patients of all ages are proactive in self-monitoring their conditions, and often enthusiastic in doing so. Patients are required to carry electronic glucose monitors with them, in order to ensure that their levels are safe prior to driving or engaging in other activities that would require

TABLE III  
CLINIC OBSERVATIONS AND THEIR RELATION TO WORKFLOW REQUIREMENTS

Observation	Patients are already self-monitoring, but have to bring their readings on paper
Implication	Allowing patients to synchronise readings on their various electronic monitors would improve the process for patients and reduce errors
Requirement	<b>Technologies should support patients' current self-monitoring</b>
Observation	Patients' medication details and recent results are not always synchronised
Implication	New technology in clinical practice would ideally allow clinicians to immediately view updates made by another clinician
Requirement	<b>Technologies should make it easy for clinical staff to communicate and collaborate with each other</b>
Observation	Patients are burdened with keeping track of many responsibilities
Implication	A function to send time-based or context-sensitive reminders could improve appointment and medication adherence
Requirement	<b>Technologies should support personalised reminders</b>
Observation	Failure to remember medication or monitoring equipment could be life-threatening
Implication	If clinicians develop reminder prompts for patients, it is vital that these arrive consistently if patients' health is at stake
Requirement	<b>Clinicians must trust the resilience of apps developed with EUD technologies</b>
Observation	Clinical nurses have very little time in between appointments
Implication	If nurses are going to employ EUD to save future time, they must be allocated scheduled time to monitor patients and track compliance
Requirement	<b>Clinicians must be allowed time to get used to new technologies</b>
Observation	Patients have a variety of comorbidities, requirements and personal schedules
Implication	A generic management app may not be appropriate for diverse requirements of comorbid patients with individual demands
Requirement	<b>Technologies should allow tailoring by individual patients</b>

concentration, which these patients accept as part of their management regime. As previously mentioned by clinicians, patients often purchase their own monitors for home use.

2) *Problems*: Contrary to the expectation of non-compliance with self-monitoring, patients are highly compliant, but face barriers in terms of memory and information overload. Two of the three patients had their medication reviewed, revealing a considerable number of drugs for managing comorbidities present in these patients. The nurse required clarification from patients on medication they were currently taking, as medication lists are sometimes not synchronised across the practice. When these discrepancies are not checked, this can result in patients reordering unnecessary prescriptions.

3) *Technology*: In terms of resources, patients were provided with a self-management plan on paper. The nurse explained that while patients were generally enthusiastic about a personalised plan, the paper often got misplaced, so that the nurse would keep a copy herself to use for discussion with patients. Indeed, technology use was limited to the nurse's patient management application. She described how some clinics send patients SMS appointment reminders, but that this is at the discretion of the clinic's management, and due to the logistics of implementation, is uncommon.

#### B. Hypertension management clinic

The hypertension management clinic had a similar format to that of the diabetes clinic, involving a nurse with expertise in hypertension, who saw three patients for their annual reviews.

1) *Self-management*: Despite similar difficulties to the diabetic patients in independent management of their treatment, hypertension patients also appeared to be proactive in doing so. All three patients were satisfied with monitoring their blood pressure readings every day, expressed interest in the results, and engaged in active discussion with the nurse, rather

than passively receiving information. The nurse explained that patients frequently get *white coat hypertension* - the artificial raising of blood pressure readings caused by the unfamiliar clinical environment. To alleviate this, they are encouraged to take their blood pressure readings at home, in a familiar context that provides the most accurate results.

2) *Problems*: Forgetfulness, particularly in medication management, was a pertinent issue noted during observation in two older patients. As discussed in the diabetes clinic, patients would order unnecessary medication, due to lack of communication between clinical staff. One patient was unsure of the medication she was regularly taking. The nurse was required to go through this patient's list of medication, asking which were actually necessary. Although appointment reminders were sometimes made via phone calls, this placed additional responsibility on nurses beyond their standard schedule.

3) *Technology use*: The use of technology again appeared to be limited to the nurse's patient management application, which did not integrate well with patients' paper-based readings, as previously described in the manual transcription, scanning and uploading of patient results. The nurse described a new system for prescription management, whereby patients receive a text message to remind them that their prescription is due. The system has so far received a positive response from patients, but is limited to prescriptions and does not take into account regularly scheduled appointments, or reminders to take medication, for example.

#### C. Summary

These observations are not an in-depth ethnographic study but instead served as a source of triangulation with clinician interviews. Table III summarises observations, their implications, and the requirements derived from interviews that they support, described in detail as follows.

The between-patient variation in skills and requirements necessitates individually tailored apps. However, *within*-patient differences of knowledge and proactive behaviour over time indicate the utility of allowing patients to tailor their apps independently. Recently diagnosed patients require considerable education and reminders to engage in treatment, but over time, their self-efficacy increases such that monitoring and medication become routine activities. Thus, continuous reminders from an app at this stage are likely to be irritating and intrusive. Allowing patients to adjust the level and type of reminders as necessary would therefore be beneficial, represented by the requirement that ***“technologies should allow tailoring by individual patients”***.

The laborious transfer from paper to electronic health records could be alleviated for nurses, but if patients have to do their own transfer of readings from glucose or blood pressure monitors into new technologies, there still exists labour on their part. Further, the requirement that ***“technologies should support patients’ current self-monitoring”*** could also streamline this process for patients themselves.

This difficulty in information transfer was also present between nurses and other clinicians. For example, changes to medication initiated by GPs were not immediately communicated through the clinic’s system, such that nurses relied on patients to provide up-to-date information. Accessing results such as blood tests also appeared to be a time-consuming process for nurses. This difficulty in communication was highlighted through interviews, motivating the requirement that ***“technologies should make it easy for clinical staff to communicate and collaborate with each other”***.

Allowing patients and nurses to work together to schedule reminders on patients’ devices for medication, appointments, and emergency equipment could be a useful feature, consistent with the requirement that ***“technologies should support personalised reminders”***. As an example, a prompt could be issued to a patient when they leave their home to remind them to take appropriate equipment with them. This further links with the importance of app reliability. Ensuring that reminders are sent to patients consistently is of particular importance, such that ***“clinicians must trust the resilience of apps developed with EUD technology”***.

The adoption of problem-solving technology must not impose additional burden on clinicians in its use. Although empowering patients to take responsibility for their healthcare would reduce the burden of unnecessary or missed appointments, it appears that the primary barrier to the adoption of novel technology is the initial burden of introduction. Nurses are still constrained by time, and as such are unlikely to monitor patients’ self-reported readings in between appointments unless specific time was allocated for them to do so. This supports the requirement that ***“clinicians must be allowed time to get used to new technologies”***.

## V. DISCUSSION

For clinicians to adopt new problem-solving technologies in practice, our interviews suggest that this is largely dependent

on the *facilitating conditions* determined by their organisation. Clinicians are constrained by the health service’s stringent requirements on app evaluation and ethical considerations. Nevertheless, the WHO’s advocacy of mobile technology’s role in healthcare and the establishment of the NHS app library, suggest that technologies that mitigate the chronic disease pandemic will be feasible in the near future.

Clinicians explained that target patients are often already active in self-monitoring, suggesting that, although such technology would be feasible, clinicians also have initial requirements that must be satisfied by software to justify the disruption of their current working practices. We briefly discuss these requirements in relation to the two overarching themes of *time* and *quality* of EUD technologies.

**Time** appears to be the most critical barrier faced by clinicians, thus the time EUD would ultimately save (*perceived usefulness*) and the time that organisations would allow for integration (*facilitating conditions*) are determining factors for adoption. The NHS, or indeed any organisation that a clinician is part of, must allocate time for a period of adjustment. However, an organisation’s willingness to do so is contingent on the assurance that it will eventually save time, and therefore money. Empirical evidence of time-saving capabilities through an NHS-supported evaluation is thus necessary. Although clinicians will still have limited time to engage in development activities, patients’ motivation to independently manage their health suggests that these patients could themselves act as developers, tailoring their management applications to their own goals and needs.

**Quality** is another overarching factor discussed. The quality of an app in terms of its functionality is a determining adoption factor (*perceived usefulness*), but particularly in terms of its reliability. A reliable app ensures that constant debugging and patient frustration are minimised, but is also necessary to ensure that apps will not potentially cause harm by malfunctioning (*facilitating conditions*). Reliability is another critical facilitating condition for organisations. Particularly in the health service, all apps must undergo rigorous evaluation to ensure that they will do no harm to patients. This is a difficult implication to address for an EUD tool, given that adoption is contingent on not just the reliability of one particular app, but on the reliability of all apps that could be developed. Evidence that clinicians and patients cannot implement harmful apps is therefore a necessary adoption factor.

### A. Limitations

Although interviews and observation offer insights beyond that of usability studies, some limitations remain. Half of the interviewees were GPs, which was a consequence of convenience sampling in our university’s school of medicine. It emerged that GPs are minimally involved in chronic disease management of patients. Nevertheless, all clinicians were well-informed on the duties of practice nurses and therefore aware of their potential motivations and constraints. Further work is required to elicit the firsthand feedback of practice nurses.



Furthermore, unlike the studies in our Related Work section, we did not receive direct feedback from individuals currently managing chronic diseases. However, clinicians provided detailed accounts of potential issues and benefits for patients, which were reflected in the observation of such patients, and were adequate for addressing adoption factors for clinicians.

Finally, as chronic disease is a global problem, we are limited in the scope of our research within the UK health service. Attitudes towards, and understanding of health technologies will vary widely across different cultures, constituting an extra dimension of ‘wickedness’. Replicating this work with international clinicians would provide insight into the breadth of this variability.

## VI. CONCLUSION

EUD platforms can support clinicians and patients to take charge of chronic disease management at a large and complex scale, where there is no clearly delineated and agreed solution for all problem owners. In this paper, we described how clinicians and patients could employ EUD to improve chronic disease management at an individual granularity, with requirements towards real-world adoption. While significant work is required to enable a real-world evaluation, our research thus far suggests a key area of global impact for EUD technologies.

## REFERENCES

- [1] M. Gusev, A. Stojmenski, and I. Chorbev, “Challenges for development of an ecg m-health solution,” *Journal of Emerging Research and Solutions in ICT*, vol. 1, no. 2, pp. 25–38, 2016.
- [2] World Health Organization, “mHealth: New horizons for health through mobile technologies,” *Observatory*, vol. 3, pp. 66–71, 2011.
- [3] Research2Guidance, “mHealth economics 2017 - current status and future trends in mobile health,” 2017, accessed August 20th 2018. [Online]. Available: <https://research2guidance.com/product-category/mhealth/digital-health-market-overview/>
- [4] M. N. Kamel Boulos, A. C. Brewer, C. Karimkhani, D. B. Buller, and R. P. Dellavalle, “Mobile medical and health apps: state of the art, concerns, regulatory control and certification,” *Online Journal of Public Health Informatics*, vol. 5, no. 3, p. e229, 2014.
- [5] M. E. Hilliard, A. Hahn, A. K. Ridge, M. N. Eakin, and K. A. Riekert, “User preferences and design recommendations for an mHealth app to promote cystic fibrosis self-management,” *Journal of Medical Internet Research*, vol. 16, no. 10, p. e44, Oct 2014.
- [6] L. Simons, A. Z. Valentine, C. J. Falconer, M. Groom, D. Daley, M. P. Craven, Z. Young, C. Hall, and C. Hollis, “Developing mHealth remote monitoring technology for attention deficit hyperactivity disorder: a qualitative study eliciting user priorities and needs,” *JMIR mHealth and uHealth*, vol. 4, no. 1, p. e31, Mar 2016.
- [7] S. C. Reid, S. D. Kauer, A. S. Khor, S. J. C. Hearps, L. A. Sanci, A. D. Kennedy, and G. C. Patton, “Using a mobile phone application in youth mental health: An evaluation study,” *Australian Family Physician*, vol. 41, no. 9, pp. 711–714, Dec 2012.
- [8] D. Tetteroo, P. Vreugdenhil, I. Grisel, M. Michielsen, E. Kuppens, D. Vanmulken, and P. Markopoulos, “Lessons learnt from deploying an end-user development platform for physical rehabilitation,” in *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*. ACM, 2015, pp. 4133–4142.
- [9] L. A. Jibb, B. J. Stevens, P. C. Nathan, E. Seto, J. A. Cafazzo, and J. N. Stinson, “A smartphone-based pain management app for adolescents with cancer: Establishing system requirements and a pain care algorithm based on literature review, interviews, and consensus,” *Journal of Medical Internet Research*, vol. 16, no. 3, p. e15, Mar 2014.
- [10] D. Swendeman, S. Farmer, D. Mindry, S.-J. Lee, and M. Medich, “HIV Care Providers’ Attitudes regarding Mobile Phone Applications and Web-Based Dashboards to support Patient Self-Management and Care Coordination: Results from a Qualitative Feasibility Study,” *Journal of HIV and AIDS*, vol. 2, no. 4, pp. 1310–1318, Oct 2016.
- [11] E. Seto, K. J. Leonard, J. A. Cafazzo, J. Barnsley, C. Masino, and H. J. Ross, “Developing healthcare rule-based expert systems: Case study of a heart failure telemonitoring system,” *International Journal of Medical Informatics*, vol. 81, no. 8, pp. 556–565, Aug 2012.
- [12] J. E. Bardram, M. Frost, K. Szántó, M. Faurholt-Jepsen, M. Vinberg, and L. V. Kessing, “Designing mobile health technology for bipolar disorder: a field trial of the monarca system,” in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, Paris, France, 2013, pp. 2627–2636.
- [13] S. W. Miyamoto, S. Henderson, H. M. Young, A. Pande, and J. J. Han, “Tracking Health Data Is Not Enough: A Qualitative Exploration of the Role of Healthcare Partnerships and mHealth Technology to Promote Physical Activity and to Sustain Behavior Change,” *JMIR mHealth and uHealth*, vol. 4, no. 1, p. e5, Jan 2016.
- [14] D. K. King, D. J. Toobert, J. D. Portz, L. A. Strycker, A. Doty, C. Martin, J. M. Boggs, A. J. Faber, C. R. Geno, and R. E. Glasgow, “What patients want: relevant health information technology for diabetes self-management,” *Health and Technology*, vol. 2, no. 3, Sep 2012.
- [15] L. Dennison, L. Morrison, G. Conway, and L. Yardley, “Opportunities and challenges for smartphone applications in supporting health behavior change: qualitative study,” *Journal of Medical Internet Research*, vol. 15, no. 4, p. e86, Apr 2013.
- [16] N. Ramanathan, D. Swendeman, W. S. Comulada, D. Estrin, and M. J. Rotheram-Borus, “Identifying preferences for mobile health applications for self-monitoring and self-management: focus group findings from HIV-positive persons and young mothers,” *International journal of medical informatics*, vol. 82, no. 4, pp. e38–e46, 2013.
- [17] D. Ben-Zeev, C. J. Brenner, M. Begale, J. Duffecy, D. C. Mohr, and K. T. Mueser, “Feasibility, acceptability, and preliminary efficacy of a smartphone intervention for schizophrenia,” *Schizophrenia Bulletin*, vol. 40, no. 6, pp. 1244–1253, Nov 2014.
- [18] Z. W. Adams, E. A. McClure, K. M. Gray, C. K. Danielson, F. A. Treiber, and K. J. Ruggiero, “Mobile devices for the remote acquisition of physiological and behavioral biomarkers in psychiatric clinical research,” *Journal of Psychiatric Research*, vol. 85, pp. 1–14, 2017.
- [19] F. Naughton, S. Hopewell, N. Lathia, R. Schallbroeck, C. Brown, C. Mascolo, A. McEwen, and S. Sutton, “A context-sensing mobile phone app (q sense) for smoking cessation: A mixed-methods study,” *JMIR Mhealth Uhealth*, vol. 4, no. 3, p. e106, Sep 2016.
- [20] G. F. Dunton, E. Dzibur, K. Kawabata, B. Yanez, B. Bo, and S. Intille, “Development of a smartphone application to measure physical activity using sensor-assisted self-report,” *Frontiers in Public Health*, vol. 2, p. 12, 2014.
- [21] P. Klasnja and W. Pratt, “Healthcare in the pocket: mapping the space of mobile-phone health interventions,” *Journal of Biomedical Informatics*, vol. 45, no. 1, pp. 184–198, 2012.
- [22] H. Lieberman, F. Paternò, M. Klann, and V. Wulf, “End-user development: An emerging paradigm,” in *End User Development*, H. Lieberman, F. Paternò, and V. Wulf, Eds. Dordrecht: Springer Netherlands, 2006, pp. 1–8.
- [23] V. Venkatesh, M. G. Morris, G. B. Davis, and F. D. Davis, “User acceptance of information technology: Toward a unified view,” *MIS Quarterly*, vol. 27, no. 3, pp. 425–478, Sep. 2003.
- [24] D. Rough and A. Quigley, “End-user development in social psychology research: Factors for adoption,” in *Visual Languages and Human-Centric Computing (VL/HCC), 2018 IEEE Symposium on*. IEEE, 2018, (in press).
- [25] V. Venkatesh and F. D. Davis, “A theoretical extension of the technology acceptance model: four longitudinal field studies,” *Management science*, vol. 46, no. 2, pp. 186–204, 2000.